# Developing resources to support shared decision making for add-on therapies in drug-resistant epilepsy

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## Introduction

- **Research dissemination** is recognised as an important and essential aspect of research.
- It ensures that a target audience are aware of the research and can effectively implement its findings.
- For clinical research, that audience includes patients, clinicians and caregivers, who will use the information to guide their clinical decisions.
- As part of our NIHR funded (6/114/26) programme, we committed to use research dissemination to engage with stakeholders (our target audience).
- We developed a **Patient Decision Aid (PDA)** to disseminate findings from multiple Cochrane systematic reviews, primarily focused on add-on therapies for drug-resistant epilepsies.

## Objective

- To disseminate our findings in a resource that facilitates and supports shared decision making.

## Initial plan

- We originally planned to produce a resource similar to a 'blogshot'.
- Blogshots (Fig. 1) are very short and concise infographics, most suited for sharing via social media streams.
- Initial feedback from the team advised that the blogshot (Fig. 2) was too short to be informative:
  - Too much text;
  - No imagery;
  - Not overly informative;
  - Not easily understandable.
- We then chose to produce a **Patient Decision Aid (PDA)**, a key resource for shared decision making.


**Figure 1. Examples of Cochrane 'blogshots'.** Blogshots are designed to be shared on social media. They concisely describe the main finding(s) of a review and provide details about the evidence, including a statement regarding the certainty/quality of the evidence.


Cochrane
Brain, Nerves and Mind

Trusted evidence.
Informed decisions.
Better health.

**Brivaracetam add-on therapy for drug-resistant focal epilepsy (2018)**

**Who is this summary for?**

This summary is for people with epilepsy that originates in one area of brain (*focal epilepsy*) and is uncontrolled by one or more anti-epileptic drugs (*drug-resistant*), who would like to discuss the use of the antiepileptic drug, **Brivaracetam (Briviact)**, in addition to their current medication, with their doctor.

**How did we generate this information?**

We reviewed data from **six** clinical trials (randomised controlled trials) on this topic. Together, these trials included **2411** participants.

**What are the main benefits of using Brivaracetam (Briviact) in addition to current anti-epileptic medication?**

We found that people who received **brivaracetam (briviact)**, in addition to their normal anti-epileptic medication, were:

- Almost twice as likely to have a 50% or greater reduction in the number of their seizures, compared to people who were given placebo (a fake, inactive drug).
- Nearly six times more likely to achieve freedom from all seizures than people receiving placebo.

**What are the main risks of taking Brivaracetam (Briviact) in addition to current anti-epileptic medication?**

During the trials:

- Slightly more people who received **brivaracetam (briviact)** withdrew from the trials due to side effects.
- Interestingly, people receiving **brivaracetam (briviact)** were not more likely to experience one or more side effects than people receiving placebo.

This suggests that although people receiving **brivaracetam (briviact)** were not more likely to experience side effects, the side effects that they did experience might have been more severe and this may have led more people to withdraw from trials.

**How confident are we that these findings are correct?**

The evidence used to reach these findings is graded and this gives us an indication of how confident we are that the finding that we have reported is accurate.

- We graded the evidence for the benefits of **brivaracetam (briviact)** to be of moderate quality meaning that we are fairly confident that these findings are accurate.
- We graded the evidence for treatment withdrawal as low quality meaning that we are not certain that this finding is accurate, however, the evidence for the number of people experiencing side effects was of moderate quality and, therefore, we are fairly certain that this finding is accurate.

**Figure 2. The resource prototype based on blogshots.** The resource produced contained more information than a blogshot, including who the resource was intended for. However, it was not fit for purpose.

## Methods

- We conducted research about the advised content and format of a PDA, using the following resources:
  - NICE guidelines and process guide[1] for PDAs.
  - International Patient Decision Aid Standards (IPDAS) Collaboration guidelines and checklist[2]
  - Cochrane brand guidelines[3].
  - Cochrane webinar titled 'Visualising Cochrane Evidence in practice'[4].

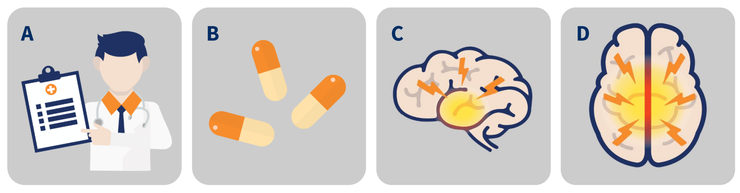



**Figure 3. Graphic images used for PDAs.** We incorporated graphics to illustrate different aspects of the systematic reviews. **(A)** A clinician with a clipboard to illustrate clinical trials. **(B)** Tablets to represent the antiepileptic drug. **(C)** A brain with electrical activity originating from the temporal lobe to signify focal epilepsy. **(D)** A brain with electrical activity originating from the centre of the brain, immediately affecting both brain hemispheres, denoting generalised epilepsy.


**Figure 4. The imagery and text used to demonstrate risk.** In accordance with the IPDAS guidelines, we reported absolute risk using simple frequencies. Risk was visualised such that the data (risk) were easily comparable between treatment groups.

## Results

- We designed and produced a PDA according to NICE guidelines and incorporated the Cochrane brand guidelines (logo, colour palette, fonts).
- We added engaging, representative and inoffensive graphic images to explain who the PDA was for and its intended use (Fig. 3).
- We reported risk as anticipated absolute effects ('x in 100' or 'x in 1000') and visualised risk using a universal person symbol (Fig. 4).
- We conveyed the certainty of evidence in a way that was understandable to lay people (Fig. 5).
- We used photographic images to emphasise and reiterate that the resource is intended to support shared decision making (Fig. 6).

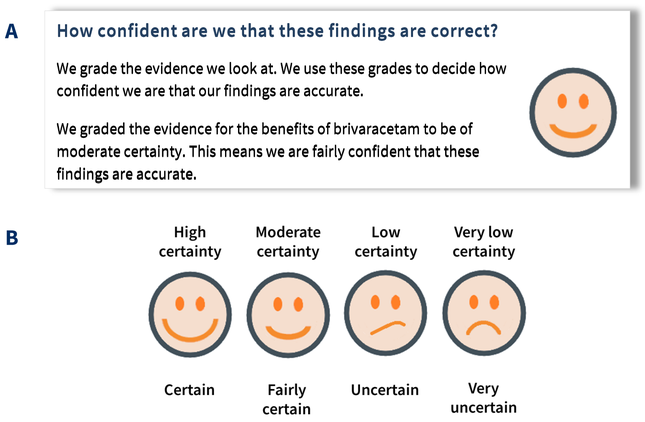



**Figure 5. Text and imagery used to convey the certainty of evidence (A)** We explained the concept of certainty of evidence without providing overly complex information about how evidence is GRADE-assessed. **(B)** We created four images to illustrate the four grades of certainty: high, moderate, low, and very low certainty.

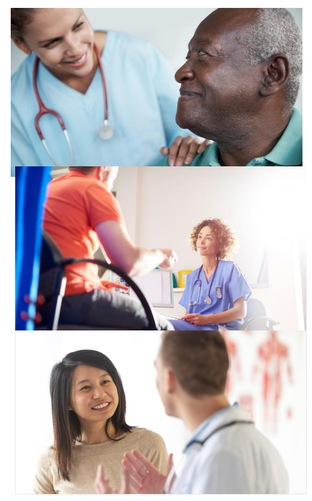


**Figure 6. Photographic images used for the Patient Decision Aids.** We used photographs of patient-clinician consultations to reinforce that the patient decision aid is intended to support shared decision making. The chosen images showed a range of ages, ethnicities and genders to be representative of all patients.

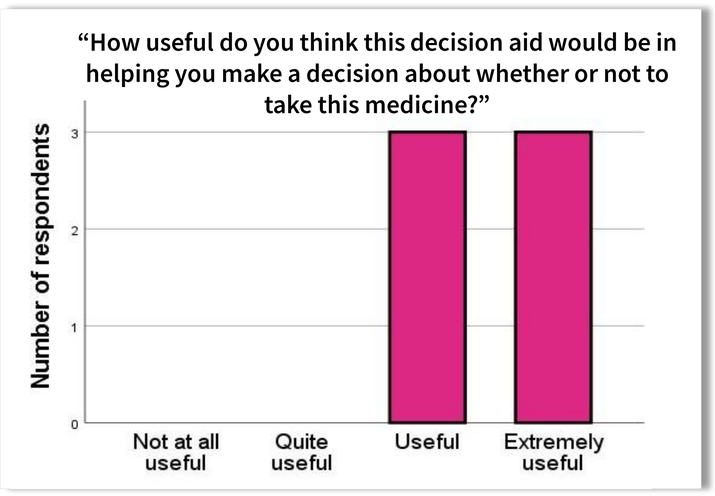
## *Difficulties encountered…*

- Maintaining concise text without losing the content or information necessary for understanding.
- Using the Cochrane colour scheme[3] whilst limiting the use of orange (difficult for users to read).
- Finding suitable images without breaking copyright.
- Presenting information that was not gained from the systematic review in a simple yet transparent way (e.g. adverse effect profile obtained from the Summary of Product Characteristics.)

**Figure 7. User testing of PDA.** A questionnaire was circulated to a small sample of 10 people either with epilepsy or carers of people with epilepsy. Respondents (n = 6) rated the PDA as useful to extremely useful in guiding shared decision making. They praised: its conciseness, clarity, the use of graphics, and its logical organisation.

## *Initial product testing*

- The resource was tested on a small sample of people with epilepsy, provided by Epilepsy Action.
- The initial feedback was very positive (Fig. 7).

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## References

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2. **IPDAS Collaboration (2006).** Elwyn, G et al. BMJ 2006;333(7565):417.
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